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Workforce development to provide person-centered care

Mary Guerriero Austrom^{a,b,c,*}, Carly A. Carvell^a, Catherine A. Alder^d, Sujuan Gao^{b,e}, Malaz Boustani^{d,f,g,h}, and Michael LaMantia^d

^aDepartment of Psychiatry, Indiana University School of Medicine (IUSM), Indianapolis, IN, USA

^bIndiana Alzheimer Disease Center, IUSM, Indianapolis, IN, USA

^cOffice for Diversity and Inclusion, IUSM, Indianapolis, IN, USA

^dMichael LaMantia, Eskenazi Health, Indianapolis, IN, USA

^eDepartment of Biostatistics, IUSM, Indianapolis, IN, USA

^fMichael LaMantia, IUSM, Indianapolis, IN, USA

^gRegenstrief Institute, Inc., Indianapolis, IN, USA

^hCenter for Health Innovation and Implementation, IUSM, Indianapolis, IN, USA

Abstract

Objectives—Describe the development of a competent workforce committed to providing patient-centered care to persons with dementia and/or depression and their caregivers; to report on qualitative analyses of our workforce's case reports about their experiences; and to present lessons learned about developing and implementing a collaborative care community-based model using our new workforce that we call care coordinator assistants (CCAs).

Method—Sixteen CCAs were recruited and trained in person-centered care, use of mobile office, electronic medical record system, community resources, and team member support. CCAs wrote case reports quarterly that were analyzed for patient-centered care themes.

Results—Qualitative analysis of 73 cases using NVivo software identified six patient-centered care themes: (1) patient familiarity/understanding; (2) patient interest/engagement encouraged; (3) flexibility and continuity of care; (4) caregiver support/engagement; (5) effective utilization/integration of training; and (6) teamwork. Most frequently reported themes were patient familiarity – 91.8% of case reports included reference to patient familiarity, 67.1% included references to teamwork and 61.6% of case reports included the theme flexibility/continuity of care. CCAs made a mean number of 15.7 (SD = 15.6) visits, with most visits for coordination of care services, followed by home visits and phone visits to over 1200 patients in 12 months.

Discussion—Person-centered care can be effectively implemented by well-trained CCAs in the community.

*Corresponding author. maustrom@iupui.edu.

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Keywords

Psychological and social aspects; Alzheimer's disease; depression

Introduction

The term person-centered care in dementia has become allpervasive, especially in the United Kingdom as it began with Kitwood's work in Bradford (Kitwood, 1997). Although Carl Rogers, one of the twentieth century's most influential humanistic psychologists, founded the 'personcentered' approach to care (Brownie & Nancarrow, 2013), it was Kitwood's work in the United Kingdom which stimulated the development of person-centered frameworks for dementia care (Hunter et al., 2013). Person-centered care is increasingly becoming synonymous with best quality or standard of care (Edvardsson, Fetherstonhaugh, & Nay, 2010). In addition, Stewart et al. (2000) demonstrated that person-centered care improves the health status and efficiency of care in a geriatric population. The shift towards a humanistic social model of care to the elderly that embraces person-centered care as its core philosophy is part of a culture change movement influencing geriatric care practices, not only in the United Kingdom but also in the United States and the Netherlands (Brownie & Nancarrow, 2013). The purpose of this paper is threefold:

- (1) to describe how we trained a competent workforce committed to person-centered care in our Aging Brain Care Medical Home (ABC Med Home), for patients with dementia and/or depression and their caregivers;
- (2) to report on qualitative analysis of our workforce's case reports about their experiences with the patients and caregivers that demonstrate person-centered care; and
- (3) to present lessons learned about developing and implementing a collaborative care community-based model using a new workforce that we call care coordinator assistants (CCAs) (Alder, Callahan, Boustani, Hendrie, & Austrom, 2012). The CCA position was specifically modeled after studies and recommendations for 'task shifting' (World Health Organization [WHO], 2008). Tasks that require less training and expertise are provided by less expensive members of the care team under the close supervision of the clinical professionals (WHO, 2008).

Why patient-centered care?

Interest in person-centered dementia care has flourished in the past two decades (Hunter et al., 2013) and in recent years concern around the need for more person-centered approaches has increased (Tobin, 2003). It seems that any new approach in dementia care has to claim to be pc (person-centered) in order to be P.C. (politically correct) (Brooker, 2004). The movement away from an institutional model of care to one that accepts person-centered care as the guiding standard of practice is part of a culture change that is impacting the provision of geriatric care services around the world (Brownie & Nancarrow, 2013). Numerous studies demonstrate that person-centered care benefits both patients and staff. For example, a 2013

systematic review affirmed that person-centered interventions are associated with positive influences on staff outcomes (satisfaction and capacity to provide individualized care); improvement in the psychological status of residents (lower rates of boredom and feelings of helplessness); and reduced levels of agitation in residents with dementia (Brownie & Nancarrow, 2013). Variations of person-centered models of geriatric care have been developed and implemented in long-term facilities around the world (International Psychogeriatric Association [IPA], 2012). Nevertheless, it has been concluded that these interventions share the following themes: elements of environmental enhancement, opportunities for social stimulation and interaction, leadership and management changes, staffing models focused on staff empowerment, assigning residents to the same staff, and an individualized philosophy of care (Brownie & Nancarrow, 2013).

Various studies describe the details and positive outcomes of person-centered dementia care models on improving behavioral and psychological symptoms of dementia (BPSD) in long-term care facilities, however, there is little research demonstrating person-centered care in community settings (Low, White, & Jeon, 2013). More community-based research of person-centered care approaches are needed, as BPSD are not limited to residents of long-term care facilities. As previously reported by Haupt, Kurz, and Janner (2000), more than 90% of patients with dementia will experience BPSD at some point during the course of their illness (Callahan et al., 2006). BPSD has been associated with caregiver burnout, nursing home placement, poor management of comorbid conditions, and excess health care costs (Callahan et al., 2006; Cohen-Mansfield, 1995; Steele, Rovner, Chase, & Folstein, 1990). We have been trying to address these issues through the implementation of the ABC Med Home model (Callahan et al., 2011, 2014; LaMantia et al., 2015) and our ongoing work with other community-based intervention models (Callahan et al., 2012).

Background

The Healthy Aging Brain Center program: foundation for the aging brain care medical home—The Indiana University Center for Aging Research (IUCAR) addresses the need for person-centered care of patients with dementia and/or depression through the Healthy Aging Brain Center (HABC). HABC expanded the definition of care of patients to include the family caregiver and provides collaborative and coordinated care inside and outside the clinical, face-to-face encounter with patients, thus offering an innovative solution to reduce dementia-related burden (Boustani et al., 2011). Given the high rate of co-occurrence of depression with dementia, the HABC also manage patients with depression using the collaborative care model established by the IMPACT study (Unützer et al., 2002) and our model of collaborative care (Callahan et al., 2006). One key component to the HABC operation is the use of a reliable tool for periodic needs assessment and the evaluation of ongoing therapy. The HABC team uses a structured biopsychosocial needs assessment to monitor the cognitive, functional, behavioral, psychological symptoms of patients and the caregiver stress (HABC-Monitor; Monahan et al., 2012) and depressive symptoms using the Physical Health Questionnaire (PHQ-9) (Kroenke, Spitzer, & Williams, 2001). The HABC monitor contains questions covering the specific care area, including memory, daily functioning, as well as falls, home safety, automobile driving and other behaviors that may become dangerous as dementia progresses where help or coping

strategies might be indicated. The total HABC Monitor score is helpful to monitor the overall biopsychosocial needs of the dyads with higher scores indicating more dementia symptoms. The PHQ-9 is a 9-item depression scale with a total score from 0 to 27 and higher scores indicating more depressive symptoms.

However, the HABC model was limited by the following constraints: (1) the clinical setting limited the number of patients that could be served not only because of the limited capacity of the clinic, but also because of the need for patients and caregivers to come to the clinic; (2) the integration of the HABC specialized services with the primary care system was incomplete; and (3) limited time and resources of the HABC often resulted in referral of patients with a primary diagnosis of depression to psychiatry. To address these constraints, the pilot program ABC Medical Home was implemented.

In 2009, in collaboration with Eskenazi Health (formerly Wishard Health Services) in Indianapolis, Indiana, the clinician scientists at IUCAR developed the ABC Medical Home, a collaborative dementia and depression care program serving 300 patients in one primary care site at Eskenazi. In 2012, the ABC Medical Home received a Center for Medicare and Medicaid Innovation Award (CMMI) to expand the pilot program to serve approximately 2000 older adults in central Indiana. The ABC Med Home differs from HABC in that it is a 'mobile memory care practice' with a major emphasis on outreach and integration within the primary care practice (Callahan et al., 2011).

The ABC medical home and person-centered care—Key to the expansion was the development of a new workforce that we call CCAs (Alder et al., 2012). The CCA position was specifically modeled after studies and recommendations for 'task shifting' (WHO, 2008). Tasks that require less training and expertise are provided by less expensive members of the care team under the close supervision of the clinical professionals (WHO, 2008).

The ABC Med Home has been committed to providing high-quality person-centered care for persons with dementia and/or depression and their caregivers. The demand for formal care and support services of an appropriately trained and skilled health care workforce for the elderly comes with the increasing prevalence of dementia (Jeon et al., 2012). Critical to the success of any program is the quality of the team members. Therefore, it was determined that CCAs would need to possess a number of key attributes at the time of hire, such as the ability to express caring, compassion, and empathy to patients and caregivers as this is essential to the philosophy of person-centered care (Brownie & Nancarrow, 2013).

Methods

The development of ABC Med Home workforce

The Training Core for the CMMI award, charged with recruiting, hiring, and training the new CCAs, realized that current hiring practices for older adult direct care workers were insufficient to meet the requirements of person-centered care (Lindquist et al., 2012) and chose to develop a new, rigorous, and innovative screening process to ensure that CCAs possessed the core interpersonal and analytical qualities required to provide excellent person-centered care (Cottingham et al., 2014). For a detailed description of how CCAs

were hired utilizing an innovative interviewing and recruitment process and then participated in a six-station Multiple Mini Interview process, developed to simulate challenging scenarios likely to be encountered in real home visits, see Cottingham et al. (2014).

Successfully hired CCAs participated in an intensive 10-day training program to prepare them to deliver the person-centered intervention within a multi-disciplinary care team. Studies have reported that clinical care providers often lack the knowledge required to apply the principles of person-centered care to everyday practice (Beck et al., 2002; Coker, 1998; Tellis-Nayak, 2007). Therefore, key to our workforce development was our training program as it provided CCAs with an understanding of person-centered care so that they could provide care to patients and their caregivers in a person-centered manner. The workforce training used a variety of methods:

(1) Training modules using didactic lectures, slides, and discussion on how to best implement the intervention protocols. Elements of the training program have been described previously, as have the intervention protocols to address BPSD that were used in the original collaborative care study (Alder et al., 2012; Callahan et al., 2006; Guerriero Austrom et al., 2004, 2005, 2006). We also incorporated role playing into the didactic sessions so that CCAs could practice administering the PHQ-9 and the HABC monitors to each other. For the CMMI Award, the training program was expanded to include the interdisciplinary, multimodal educational methods described below as well as teaching CCAs how to use the electronic medical record system.

(2) Simulation sessions utilizing standardized patients in our Indiana University School of Medicine simulation center. Having trainees demonstrate their ability to listen and to show compassion and empathy while being videotaped allowed staff the opportunity to watch their performances and provide in feedback. Following feedback, trainees were asked to repeat the session and were videotaped again. Trainers were able to watch the simulations remotely and provided feedback in both one-on-one and group settings.

(3) Clinical immersion included shadowing current staff in both HABC and home settings. Following the immersion sessions, which were completed in pairs – a CCA with a current staff member – as scheduled visits with patients and caregivers became available. Following each clinical immersion session (3 in 10 days), CCAs participated in large group debrief sessions with the trainer and the current staff members discussing their experiences. These sessions were useful for those CCAs who had not yet participated in a home visit to learn about others' first experiences going into people's homes. Common reservations about home visits included how to establish rapport, what to do during the first home visit, safety and health issues and emergency response procedures. Because this program is part of a larger health system, some of these topics were covered by the health system, new employee orientation programs include health and safety and emergency response procedures, which we reinforced. We were able to augment that training with program specific information about home visits and initial visit protocols provided by the project and medical directors.

(4) Specialized training and development including the IMPACT model of depression care and palliative care training were offered in large group format and included didactic lectures with PowerPoint and role playing in pairs with in the large group setting. CCAs received additional training in depression and palliative care enabling them to help coach and activate patients with depression and to discuss and assist with advanced care planning issues (Alder, LaMantia, Austrom, & Boustani, 2015). These additional training programs were implemented within the first 6 months (IMPACT depression training) and 24 months (palliative care training) of the demonstration project, respectively, and are described below.

- a. IMPACT model (Unützer et al., 2002; <http://impact-uw.org>) of late life depression. The ABC team worked with the patient's primary care physician to develop and implement a depression treatment plan. If patients do not improve, the patient may be referred to psychiatry. The treatment plan includes:
 - provide education about depression to the patient and caregiver;
 - coach patient and caregiver in behavioral activation and scheduling pleasant events;
 - offer problem-solving therapy (delivered by trained and licensed staff, the registered nurse [RN] or masters of social work [MSW]);
 - monitor depression symptoms using the PHQ-9 for treatment response;
 - complete a relapse prevention plan with each patient who has improved; and
 - antidepressant therapy is prescribed by the patient's primary care provider if appropriate and necessary.
- b. The palliative care training was developed and delivered by the palliative care service at Eskenazi in conjunction with our colleagues in education researchers. It was primarily focused on training the CCAs and care managers to initiate and facilitate conversations with patients and families about end of life care and decisions to be documented with advance care planning tools. The CCAs, because of their relationship with the patients and caregivers began discussions about choices in end of life care and enter it into the electronic medical record (EMR). The care managers and physicians would follow up on the preliminary discussions.

Responsibilities of newly trained workforce

The training program addressed the demand for an appropriately trained and skilled health care workforce capable of the meeting the need for care and supportive services for persons with dementia and/or depression and caregivers (Jeon et al., 2012). CCAs work in teams led by an RN and social worker care coordinators (CCs) who both supervise and support the CCAs in every aspect of care delivery. CCAs are responsible for assisting CCs in scheduling

and performing patient and caregiver visits, administering the biopsychosocial needs assessment, delivering care protocols, monitoring medication adherence, and managing data entry (Cottingham et al., 2014). To carry out these responsibilities CCAs are provided with a mobile office, enhanced medical record-ABC (eMR-ABC) software, information on community resources and team member support. Details of the intervention and its tools, including care protocols have been previously published (Alder et al., 2015; Boustani et al., 2011; Callahan et al., 2011, 2014; Cottingham et al., 2014; Frame, LaMantia, Bynagari, Dexter, & Boustani, 2013; French et al., 2014; Guerriero Austrom et al., 2004, 2005, 2006; LaMantia et al., 2015; Monahan et al., 2012); therefore, we provide only a brief description of this here. The use of the 'mobile office' in the CCAs day-to-day work allows them to meet patients at their homes, their primary care doctor's office, or any other safe location of their choosing. This freedom and flexibility in scheduling permits CCAs to make decisions based on the physical, emotional, and psychological comfort of patients and caregivers. The team has been trained to use the PHQ-9 (Kroenke et al., 2001) and HABC Monitor (Monahan et al., 2012) to monitor patients' and caregivers' symptoms and response to treatment.

Following the initial visit, the CCA meets with the RN and social worker CCs to review the results of the initial assessments and determine the severity of the patient's illness and related needs of the patient and caregiver (Alder et al., 2015; LaMantia et al., 2015). Together, they develop an individualized care plan which may include any of a variety of tools tested in the original clinical trials, including medications (prescribed by the primary care provider at the recommendation of the RN CC), non-pharmacological caregiver interventions, self-management educational materials for both patients and caregivers, behavioral activation, relapse prevention, problem solving therapy (PST), and coordination with resources in the community (Alder et al., 2015; Guerriero Austrom et al., 2004, 2005, 2006; LaMantia et al., 2015). The care plan is initiated by the CCA at the next scheduled visit.

A key component is the patients' with dementia and/or depression and caregiver assessments completed at each visit and entered into our eMR-ABC. The eMR-ABC tracking system is critical to person-centered care as it allows the CCA and the care team the ability to move between population and individual data. While we are providing population health, we are able to deliver individualized person-centered care: the eMR-ABC creates a registry of all patients enrolled in the program, tracks appointments, alerts the CCs of any acute care visits, monitors the current symptoms of the patient and informal caregivers, recommends individualized care protocols (Guerriero Austrom et al., 2004, 2005, 2006) based on current symptoms, and provides timely feedback on the performance of the ABC program in managing the health of its population (Boustani et al., 2011; Frame et al., 2013).

Our teams often encounter challenging social issues when meeting patients in their homes (for example, problems with housing, utilities, meals, and transportation are common) that must be addressed before the patient or the family caregiver can focus on dementia and/or depression care. This is consistent with some of our previous work that has found caregivers often have stressors unrelated to the provision of care to a family member with dementia (Guerriero Austrom et al., 2014). Our teams necessarily rely on relationships with existing

local community organizations to address patient and caregiver needs. For example, one of our CCs and three CCAs are embedded in the local Area Agency on Aging (AAA) which facilitates coordination of social services with local providers. It is important to note that our academic medical center and the local AAA have a long history of collaboration in serving this population. The importance of this positive, long standing relationship cannot be underestimated.

We believe that once you have an excellent team in place, you must take care of them. If you take good care of your team, then, they, in turn, will take good care of your patients. Previous research has shown that managers who behave in a person-centered manner towards their staff will listen to and show concern and regard for them and thus, are more likely to engender staff loyalty, commitment, and job satisfaction (Tellis-Nayak, 2007). Supporting team members and providing regular opportunities to meet, talk about stressors and get their input on how the program is working and what challenges and opportunities they see, helps to develop a strong sense of team and ownership of the program. Previous studies have reported that support offered to staff in their workplaces facilitated person-centered care planning and practice. In particular, the importance of management support to implement person-centered care cannot be underestimated (Jeon et al., 2009, 2012); it is a necessary ingredient for improving staff performance and achieving care quality (Chenoweth, Jeon, Merlyn, & Brodaty, 2010; Harvath et al., 2008; Jeon et al., 2010). Therefore, the leadership of ABC Med Home meets with the CCAs regularly; for example, the medical director participates in weekly team meetings led by the CCs; the dementia care educator meets with the CCAs on a monthly basis and is available as needed. If the care staff members believe that they have been provided with sufficient resources and if they feel listened to by their managers, the result is less staff burnout as well as improvement in their overall sense of well-being (Jeon et al., 2012). While we have not measured staff sense of well-being directly for this paper, our staff retention rates have been excellent. After one year of operations, only 1 of the 20 full time equivalents (FTEs) had left the program and that individual, although doing an excellent job, chose to move to an administrative position within Eskenazi. By the end of second year, four more CCAs had departed: two were promoted to other positions within Eskenazi; one moved out of state; and one was unable to return from medical leave (Note: two positions are half time, so we began with 21 CCAs for 20 FTE positions and reported on 16 CCAs for this paper).

Methods

Institutional review

The project was submitted to the Indiana University Purdue University at Indianapolis Institutional Review Board upon receipt of the CMS Innovation Award. Because the award was a demonstration project and not considered research, the project was exempt from review.

CCA involvement in ABC Home Med intervention

The ABC Med Home uses standardized educational materials, self-management strategies, and supportive services to help manage, reduce, and prevent problematic symptoms as well

as reducing the physical and psychological burden on the caregiver. This focus on the patient and caregiver begins with the first patient/caregiver visit and is provided continuously throughout the course of the disease. The program has been described elsewhere (Alder et al., 2012, 2014, under review) and the materials are offered to the caregivers in a guidebook/manual format titled, *Aging Brain Care: Caregiver Resource Handbook*, to help the family navigate through the disease process (Aging Brain Care, 2012). In addition, caregivers are encouraged to participate in a monthly support group and to utilize other resources available through the local chapter of the Alzheimer's Association.

During the initial visit, the CCA completes multiple assessments to determine the severity of the patient's dementia and/or depression and the needs of the patient and caregiver, including the mini mental status examination, the PHQ-9, and the caregiver and self-report versions of the HABC Monitor. During follow-up contacts, the CCs and CCAs routinely measure and monitor the patient's response to treatment using the PHQ-9 and the HABC Monitor. Comparisons among patients with dementia only, depression only or both dementia and depression were conducted using analysis of variance for continuous variables and Chi-square tests for categorical variables.

Results

CCA demographics

We trained and deployed 16 CCAs (mean age, 41.5 years) 13 females and 3 males; 8 CCAs identified themselves as Caucasian and 8 as African-American; 10 CCAs had either 2 or 4 year college degrees and 6 had high school diplomas. Additional demographic details are included in Table 1.

Patient population

Patients aged 65 or older are selected for the ABC Med Home program if they meet the following: is a Medicare or Medicaid beneficiary, have had at least one visit to one of Eskenazi's primary care practices within the last two years, and have had at least one dementia and/or depression International Classification of Diseases (ICD-9) diagnosis code. Eligible patients were initially identified from Eskenazi's billing records. With the approval and endorsement of the hospital leadership, primary care physicians were presented with lists of their patients who met program qualifications and asked to exclude any patients that they did not wish to enroll in the program. Patients and their caregivers were then contacted and asked to consent to enrollment in order to receive visits from our CCAs (La Mantia et al., 2015).

There were 1213 patients with dementia ($n = 233$), depression ($n = 876$), or both dementia and depression ($n = 104$) enrolled in the ABC Med Home program between 1 July 2013 and 30 June 2014. In Table 2, we present demographic characteristics, history of comorbid conditions, and baseline measures of disease severity, including mean HABC monitor scores and PHQ-9 scores by the three patient groups. Mean patients' age was 74.5 years ($SD = 7$), with 77% being female and 45.8% African-Americans. The mean number of comorbid conditions was 3.4 ($SD = 1.8$). In Table 3, we present the types of services delivered and

changes in severity scores as measured by the HABC-Monitor (Monahan et al., 2012) and the PHQ-9 (Kroenke et al., 2001). These are two validated instruments that respectively measure stress in caregivers of dementia patients and patients' depression symptoms. Mean numbers of visits was 15.7 (SD = 15.6), with the most visits made for coordination of care, followed by home visits and telephone visits. Coordination of care visits included telephone calls, emails, mailings, faxes, and/or in-person communication related to the coordination of care often with third party social services providers, e.g. inquiring about primary care appointments, scheduling transportation, appointments, services available from the Area Agencies on Aging, Adult Day providers etc., but communication with patients and caregivers are included in this category if the communication was related to following up on the plan of care and does not involve administering assessments. Home visits include visits made to patients and caregivers in their homes including a visit made in the common areas of a patient's assisted living facility. Telephone visits include calls made to patients and caregivers during which assessments are completed, e.g. completing a PHQ9 by phone. These do not include calling a patient for scheduling a visit or attempted phone calls made. Clinic visits include visits made to the patients in the primary care and specialty care clinics including visits made in the waiting room and seeing a family member in HABC.

The estimated slopes for disease severity scores were all negative indicating improved symptoms on all measures. Further details of our evaluation of the patient and caregiver response to our intervention have been described (LaMantia et al., 2015).

Qualitative data analysis

As part of the CMMI quarterly reporting requirements, CCAs are asked to share a case that represents a success story, a lesson learned, and/or demonstrates the impact of the intervention. From 31 March 2014 through 30 June 2014, 73 quarterly case reports were completed by the CCAs and included in the qualitative analysis. Each report was read; grammar and typos were corrected, and were entered in QSR NVivo 10 (Bergin, 2011). Two reviewers with backgrounds in psychology reviewed each case to identify recurrent conceptual codes or themes that were considered inherent to person-centered care. Each of these themes was identified within the case reports by association with words or language inherent to that theme; and each instance that a theme was identified was recorded. Both reviewers underwent training within the NVivo software in order to conduct the review and independently reached consensus on the following six themes (interrater reliability was .88).

- (1) Patient familiarity, understanding, and communication – represents the ability of the CCA and the team to get to know a patient and their individual needs and subsequently able to tailor care, communication, and interventions to that patient.
- (2) Patient interest/autonomy and engagement encouraged – the CCAs encourage patients to engage in activities that promote well-being and autonomy whenever possible based on the patients' self-identified interests or identified by the caregiver. Patient safety is of utmost concern when dealing with patients with dementia, therefore, if self-identified activities included activities that might put

the patient's safety in jeopardy, alternative activities or alternative ways of delivering the activity were identified.

- (3) Flexibility and continuity of care – CCAs are able to foster a meaningful relationship with patients over time and view this as an important aspect of care. In addition, it represents the ability to adapt to different and, often, challenging environments while maintaining continuity in the care of the patient and caregiver.
- (4) Caregiver support and engagement – CCAs give a patient's primary caregiver support and recommend respite that was important for the overall well-being of the patient and highly appreciated by patient caregivers.
- (5) Effective utilization and integration of training – CCAs demonstrate that they can apply the training they received into their daily interactions with patients, this included but was not limited to: administration of PHQ9 and HABC monitors, use of the eRM-ABC, application of standardized protocols, and discussion of palliative care.
- (6) Teamwork – CCAs work as part of a team, and constant communication with team members and supervisors resulted in better care for their patients.

Qualitative results

Seventy-three case reports were entered into the NVivo software package. Sources refers to the number of times a theme was identified in 1 of the 73 cases; references refers to the total number of a times a theme appears in the cases, a theme can appear in a single case more than one time. As seen in Table 4, patient familiarity, understanding, and communication was mentioned most often in the CCA cases (91.8%) and referred to more than twice as often as the other themes. For our group, teamwork was a very important recurring theme and was identified in 67.1% of the cases.

Examples of case reports with person-centered care themes

Below are examples of several case reports from the CCAs that highlight person-centered care and interventions offered by this program.

Patient familiarity, understanding, and communication – the case below demonstrates how the CCA was able to get to know the patient and tailor their encounters to best suit the needs of the patient. We note that many of patients in the Eskenazi Health system are initially reluctant to let people into their homes due to concerns about safety and privacy, fear of being removed them from their homes, and other concerns related to distrust. However, with a little patience over a few visits, the CCAs reported that patients learned to trust them and the CCAs soon became important members of the care team and trusted by the patient and caregiver.

Mrs K is a patient that has a diagnosis of depression. She will only meet me at (a local eatery) because of her living situation. Once upon a time, not long ago, her son was very well off and lived in a huge house in the (upscale) area. She lived there with her son and enjoyed a great life – but then he lost his job, his home, and

everything else. I have seen Mrs K twice and she has opened up a lot. I learned that she lost a daughter to a heart attack which bothers her still. Mrs K is a very strong lady. She is a 'look on the brighter side' type of person. At our last visit, she actually said she would invite me to where she was staying. I am learning that it takes patience and time with our population. They will open up and we will be able to help them when they are ready. Working with Mrs K has helped me when I deal with other patients as well.

The following case illustrates that building trust and being familiar with the patient's situation is integral to being able to successfully aid the patient.

Mr B is one of our patients who suffer from dementia. I first visited him in January 2013 and his mini mental state examination (MMSE) was 18 at that time. In June 2013, he was hospitalized and our nurse visited him following his discharge from the hospital. The MMSE administered during that visit was 23.

Mr B was very distrustful and nervous about letting people into his home. He dialed 911 frequently because he thought someone was coming into his home when he was gone and stealing items from him. Mr B's landlord (at his senior apartment) threatened to evict him if he continued calling 911. Now instead of dialing 911, he calls me. I reassure him and he does not call 911.

The success in this story is about building a relationship with your patient where they trust you enough to let you help them. Mr B is still living in his senior housing and letting me visit. I visited Mr B after the nurse's visit in June. He was very alert that day and stated that he really appreciates this program.

Patient interest/autonomy and engagement encouraged – the case below illustrates that, when able, encouragement and support of a patient's interests will help to improve quality of life.

My patient is a 65-year-old female. This patient has suffered on and off from depression her whole life. When I first talked to her on the telephone, she was hesitant about letting someone come out to her senior living apartment, but she finally agreed to schedule a visit. From the first visit, we began building a relationship. This patient has always been very thankful for our program and she expresses her appreciation every time we talk. During the year that I have seen her, her PHQ-9 score has dropped six points. She was receptive to the behavioral activation and relapse prevention protocols; she has worked very hard at staying active and learning to recognize the signs that indicate her depression may be coming back. Last time I saw the patient, she was in very good spirits. The patient had started volunteering at a day care on her side of town. She was so excited to share this news with me and told me how well she has been doing. She also told me that if it had not been for me and the ABC program, she would not have made such progress. Sometimes people just need a little encouragement to get through the difficult times in life, someone to stand by them and show they care. I am a very proud of the work I have done with this patient.

Flexibility and continuity of care – the case below demonstrates that over time with the CCA providing continuity in care, a patient will be more receptive to hearing difficult conversations and making difficult decisions.

Incorporating the palliative care training into my visits with patients has been very challenging, but also very rewarding. In the initial stages of training, I never thought I would be able to talk to my patients about death and the wishes and goals they may have. I just imagined depressed patients becoming even more depressed thinking and talking about death. However, for the most part, patients have been very interested in having these conversations. I bring up the issues and my patients really want to fill out forms and think of ways they can get things in order.

I had a female patient that I was working with complete Health Care Representative form. I asked her who she would want to make medical decisions for her in the event that she was unable to make them for herself. She jumped right into the conversation by telling me who was not capable of making decisions and why. Then she completed the HCR form and told me to make sure it gets into her file. On the next visit we did the Go Wish activity. I have also been able to document that information and encouraged her to share it with her family. She is now working on funeral arrangements and getting her important documents in order so her family does not have to deal with it alone. I think it is great that the small conversation that we had really got her thinking about the future.

I have had a few patients that have not been as willing to talk about advance care planning with me. Even though they have not been ready to talk about it, they agree it is something that needs to be discussed. That gives me the opportunity to revisit the topic at a later visit. I am so excited to have this additional training. I feel like it gives me one additional way to assist my patients.

Caregiver support and engagement – below is an illustration of the importance of building a relationship with the caregiver and family and how that positively impacts the family system.

My initial visit with my patient and daughter was in October 2012. She had been diagnosed with Alzheimer's disease. My patient was non-verbal and not walking. Her daughter asked if we could help with getting her a wheelchair and hospital bed. I talked with my social worker and also with Central Indiana Council on Aging (CICOA) and we were able to help provide the hospital bed and wheelchair for my patient to make it easier for the family to take care of her. They were very grateful for our help. My patient just recently passed and I visited the family to pay my respects. They were very thankful for all that I had done and for the ABC program.

Effective utilization and integration of training – the case below shows how the CCA was able to use their training to connect a patient to much needed resources.

I have a patient that I just started seeing that we have had a hard time reaching. Upon seeing this patient, she reported to us that she was on the verge of being evicted from her apartment due to the clutter in her home. The patient is wheelchair-bound and unable to ambulate on her own. She has a hard time navigating through the community and her own apartment. Getting to and from her

doctor's appointments was a challenge and everyday tasks became very difficult for her to complete.

It was clear the patient needed physical assistance not only for her personal care, but her daily living needs as well. Through our program, we were able to connect the patient to home-delivered meals, transportation to her doctor's appointments, and in-home assistance to get her bathing needs met. We were also able to find someone to help her organize her apartment so she would not get evicted.

Teamwork – following is an excellent example of how a CCA interacts with multiple members of the team to provide the best possible care for the patient.

I had a hard time getting in touch with this 75-year-old female with depression. So I went to talk to one of the social workers in the Center for Senior Health and he told me about the patient. I went by the patient's house and she was there but there was a lock on the gate. I called her and she came to the gate. I introduced myself and then talked more with her. The patient started to tell me what was going on and I just listened to her. She had a lot going on and she really needed some help. I tried to complete the initial assessments, but could not do an MMSE because patient could not stay on track. Then I saw a spot on her leg and it did not look good. I was very worried about the patient's leg so I talked to the nurse and the social worker about what I had seen. I tried to call the patient but she did not answer the phone – so we all just went to see the patient about her leg. The nurse cleaned up the patient's leg and gave her medication for the wound. The social worker talked to her about her Medicaid. I helped the patient get enrolled in the CICOA Way2Go program so she can get transportation to the doctor. I have also been working with Center for Senior Health to make sure the patient gets all the help she needs.

Discussion

The purpose of this paper was threefold: to describe how we developed a competent workforce committed to providing person-centered care in the ABC Medical Home, for persons with dementia and/or depression and their caregivers; to report on the qualitative analysis of CCA's case reports for themes of person-centered care; and to share lessons learned about developing and implementing this type of collaborative care model in a large urban primary care system. Our qualitative analysis showed that person-centered care can be effectively delivered by CCAs in community settings. More specifically, the theme of patient familiarity, understanding, and communication was referenced in 91.8% of the CCA case reports indicating that CCAs were able to demonstrate understanding and communication of their patients and were able to tailor their interventions to patient needs. In addition, the importance of teamwork was identified in 67.1% of the case reports, demonstrating the value of our CCAs working in small teams to meet the needs of patients and caregivers by relying on the support of their teammates. These analyses support the previously mentioned framework of person-centered care themes (Brownie & Nancarrow, 2013) and the ability of our own workforce to demonstrate and implement person-centered care in community settings. Additionally, objective measures of depression, BPSD, and caregiver stress showed rates of decline over the 12 months of care analyzed for this paper. The results support our

view that person-centered care can be effectively implemented in community settings to improve outcomes, including BPSD, specifically in patients with dementia and/or depression.

Successful program implementation – lessons learned to date

The CCA case reports and our experiences to date have demonstrated not only the importance of providing person-centered care but also the importance of patient engagement and relationship building, support of hospital leadership, staff support and development, and the measurement of program outcomes to the successful implementation of the program.

Patient engagement and relationship building—The IPA recommends that patients be given opportunities for social interaction and meaningful activity so as to decrease the risk of triggering BPSD (IPA, 2012). CCAs and CCs have developed innovative ways to successfully contact patients and caregivers and have worked diligently to develop effective ways of introducing themselves and the program and services. Over the course of the program, CCAs have developed close and meaningful relationships with our patients that the physician simply does not have the time to do. These trusted and close relationships are an important and powerful tool that our health care team uses to provide patient-centered care. In team meetings, the group discusses ways to overcome barriers in developing the relationships and how they can use these relationships as a means of getting our patients connected with other necessary health care services and community-based providers. Our medical director notes that the relationships developed by the CCAs are an important and critical piece to providing care.

Support of hospital leadership—This was key to successful program implementation as it engages primary care providers in person-centered care with the involvement of their patients. This support is rooted in a partnership between Eskenazi and the IUCAR that began more almost two decades ago and has transformed the way older adults are cared for at Eskenazi (Callahan et al., 2011). The ABC Med Home Program strengthened the bond between the hospital leadership and the care teams via the mobile office. CCs and CCAs are accepted as co-managers of patients and vital members of the primary care team (Alder et al., 2014).

Staff support and development—In order for people to do their jobs well, they need to have support and the resources necessary to do a good job (Guerriero Austrom et al., 1999, 2000). Therefore, the dementia care educator meets with the CCAs once per month for a ‘staff support’ group. CCAs have the opportunity to share any concern about any issue in as safe and confidential space. CCAs also receive regular development opportunities, including ‘booster’ training in the IMPACT program (depression and behavioral activation) and palliative care, and the opportunity to attend all programs offered by the Indiana Alzheimer Disease Center on campus including the scientific and caregiver symposia.

Measurement—Resources, such as eMR-ABC, are made available to CCAs to facilitate the care of our patients and caregivers. The eMR-ABC links our measures of success to an

electronic tracking system that allows us to continuously monitor outcomes so we can make the timely adjustments in care plans required to improve results.

Future directions

Low et al. (2013) noted that the challenges of delivery of person-centered care are recruiting and retaining skilled staff, lack of good training and workforce shortages. We believe that our program addresses some of these issues with the recruitment, selection, training, and continued development of our CCAs (Cottingham et al., 2014). Our staffing model features a team of five CCAs managed by an FTE RN and .5 FTE MSW under supervision by a medical director. Because a team-based approach in the education of person-centered care is central to our model, all didactics, simulation, and clinical immersion sessions included entire teams. The next important step for our work is to determine best possible methods of dissemination of the program.

Feedback from both patients and caregivers is essential for future program development and quality improvement. The ABC Med Home Consumer Advisory Board (comprised of patients, families, and their advocates) is convened every six months to provide valuable feedback and suggestions to improve the experience of patients and caregivers. Information collected from this group has been helpful in addressing the concerns of patients and caregivers. We plan to use this information to make informed decisions about potential program augmentation and/or modifications as the CMMI award has been recently completed (although outcome data analysis has not yet begun). Although at this time only 30% of the original CCAs remain in place in the Eskenazi Health system, we experienced very little turnover in our staff until this year. Six of the eleven individuals who are no longer with our program left in 2015 after two years of service. It is also notable that among those 11 individuals, 6 left to accept higher paying positions within Eskenazi, 2 left for medical reasons, 1 moved outside of the state, and 1 accepted a position outside of Eskenazi in another field upon completion of her bachelor's degree. Only one CCA made a lateral move within the health system and that occurred within the first 3 months of the program after she determined that she was not comfortable doing home visits.

The future is promising for the ABC programs at Eskenazi Health. Eskenazi Health has committed to continuing the program following the completion of the CMMI Award. Hospital leaders have recently announced plans to fund a new Center for Brain Care Innovation with the ABC Med Home and the HABC as two of the four flagship programs of the new center. Toward that end, the ABC programs have been asked to develop a plan for expanding services to all patients with cognitive impairment across the state. Our CCA staff are included in the planning for the expansion.

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Table 1

Demographic data for CCA.

Variables	Eskenazi (<i>n</i> = 12)	Arnett (<i>n</i> = 4)
Mean age	43.5 (SD = 11.5), range: 30–61	42 (SD = 14.0), range: 25–59
Female, <i>n</i> (%)	10 (83.3)	3 (75.0)
Marital status, <i>n</i> (%)		
Married	8 (66.7)	3 (75.0)
Single	3 (25)	1 (25.0)
Divorced	1 (8.3)	0
Education, <i>n</i> (%)		
High School	5 (61.7)	1 (25.0)
Associate degree ^a	3 (25)	0
Bachelor's degree ^b	4 (33.3)	3 (75.0)
Race, <i>n</i> (%)		
African-American	7 (58.3)	1 (25.0)
Mean years of professional experience	11.9 (SD = 9.9), range: 2–30	20 (SD = 14.7), range: 5–40
Median start date	8 October 2012 (1 August 2012–1 August 2013)	27 October 2013 (1 December 2012–3 November 2014)

^aMajors for associated degrees for Eskenazi: certified surgical technologist (*n* = 1), general studies (*n* = 1), medical assistant (*n* = 1).

^bMajors for Bachelor's degree for Eskenazi: health care management (*n* = 1), information systems (*n* = 1), biology (*n* = 1), music education (*n* = 1); for Arnett: psychology (*n* = 2), sociology (*n* = 1).

Table 2

Baseline characteristics of patients enrolled in ABC Medical at Eskenazi Health who had visits between 1 July 2013 and 30 June 2014.

	All subjects (<i>n</i> = 1213)	Dementia only (<i>n</i> = 233)	Depression only (<i>n</i> = 876)	Dementia and depression (<i>n</i> = 104)	<i>p</i> -value
Demographics					
Age, mean (SD)	74.5 (7)	79.2 (8)	73 (6)	76.4 (7.8)	<.0001
Female, <i>n</i> (%)	934 (77)	153 (65.7)	710 (81.1)	71 (68.3)	<.0001
Black, <i>n</i> (%)	556 (45.8)	142 (60.9)	364 (41.6)	50 (48.1)	<.0001
Comorbid conditions, <i>n</i> (%)					
Arthritis	86 (7.1)	10 (4.3)	68 (7.8)	8 (7.7)	0.1801
Cancer	353 (29.1)	62 (26.6)	265 (30.3)	26 (25)	0.3481
Coronary artery disease	472 (38.9)	86 (36.9)	348 (39.7)	38 (36.5)	0.6429
Congestive heart failure	373 (30.8)	74 (31.8)	272 (31.1)	27 (26)	0.5303
Chronic obstructive pulmonary disease	389 (32.1)	56 (24)	302 (34.5)	31 (29.8)	0.0088
Diabetes	682 (56.2)	123 (52.8)	505 (57.6)	54 (51.9)	0.2698
Hypertension	1142 (94.1)	214 (91.8)	836 (95.4)	92 (88.5)	0.0041
Liver disease	57 (4.7)	10 (4.3)	41 (4.7)	6 (5.8)	0.8382
Renal disease	230 (19)	53 (22.7)	160 (18.3)	17 (16.3)	0.2331
Stroke	372 (30.7)	83 (35.6)	242 (27.6)	47 (45.2)	0.0002
Mean number of comorbid conditions per person (SD)	3.4 (1.8)	3.3 (1.8)	3.5 (1.8)	3.3 (2)	0.4197
Measurement of disease					
Mean HABC monitor score (SD)	13.2 (13.1)	15.3 (15)	11 (10.4)	13.5 (13.5)	0.0506
Mean PHQ-9 score (SD)	4.1 (4.3)	2.6 (2.9)	4.5 (4.5)	4.1 (3.9)	<.0001

^aSample size with measures.

Table 3

Types of services provided and changes in disease severity.

	All subjects (<i>n</i> = 1213)	Dementia only (<i>n</i> = 233)	Depression only (<i>n</i> = 876)	Dementia and depression (<i>n</i> = 104)	<i>p</i> -value
Types of visits ^a					
Coordination of care	5.6 (6.3)	6 (7)	5.3 (5.7)	7.7 (8.8)	0.0008
Hone visit	4.2 (4.6)	4.3 (4.6)	3.9 (4.4)	6.4 (5.5)	<.0001
Phone visit	4.1 (4.9)	4 (4.6)	4 (4.5)	5.7 (8)	0.0035
Clinic visit	0.6 (1.4)	1.1 (1.7)	0.3 (0.9)	2 (2.3)	<.0001
Total number of visits	15.7 (15.6)	16.7 (16.9)	14.5 (13.6)	23.9 (23.7)	<.0001
No. of months of observation, <i>b</i> mean (SD)	12.2 (8.6)	14.8 (10.5)	10.8 (6.9)	15.5 (11.3)	<.0001
Annual changes in measurements ^c					
HABC monitor slope (SD)	-2 (2.5)	-2.5 (2.8)	-1.9 (2)	-1.3 (2.8)	0.0400
PHQ-9 slope (SD)	-0.4 (0.7)	-0.3 (0.5)	-0.5 (0.7)	-0.4 (0.7)	0.0111

^aCounts all visits.^bFrom the time of the first evaluation (with at least one of the six measures) to time of last visit between 1 July 2013 and 30 June 2014.^cSample sizes vary by measure.

Table 4

Frequency and percentage of themes of person-centered care in CCA reports.

Theme	Number of sources (<i>n</i> = 73)	Number of total references
Patient familiarity, understanding and communication	67 (91.8%)	154
Patient interest/autonomy and engagement encouraged	19 (26.0%)	26
Flexibility and continuity of care	45 (61.6%)	67
Caregiver support and engagement	21 (28.8%)	48
Effective integration of training	42 (57.5%)	68
Teamwork	49 (67.1%)	73